

2/6/2023

Hello, my name is Carissa Decelles, and I'm here today to testify to the importance of the SB-82 bill as someone whom it would directly impact.

There are a few things people tend to first notice about me when we meet – the first is my service dog (for obvious reasons - hes adorable), second my wheelchair, and most recently a very sophisticated robot arm that is now attached to my chair. All of these things help me navigate the world. I live my life with a profound disability called Spinal Muscular Atrophy or SMA, which is a type of Muscular Dystrophy. This is something that I've had since birth and is progressive. Is it considered a profound disability because physically, I need help or assistance with essentially all aspects of daily living and self-care... from big things like bathing, dressing, and going to the bathroom... to small things like doing my hair, or making sure the things I need are within reach, or even opening a door.

Most people, I think, would or do assume that these limitations would negatively impact my ability to thrive as a person, in society. The world we live in is not exactly designed with people like me in mind... so yes, it is absolutely harder – but I learned to navigate obstacles and think outside the box at a very early age in life.

While all of the limitations I mentioned earlier are very true, I do not really think of myself as being “profoundly disabled,” – in fact, it's rare that it ever even crosses my mind. I am an incredibly independent person and live my life as such.

I live independently. I drive my own vehicle with adaptive technology. I am the youngest Art Director ever hired by the brand management agency that I have worked for here in Connecticut for the past 7 years. I am a freelance designer and consultant. I am the President of a non-profit that trains service dogs for people with physical limitations. I am the Vice President of another non-profit that connects creative professionals and students through networking events and mentorship. In 2020 I was honored as one of Connecticut Magazines 40 under 40. My most recent venture is joining a group of people who are starting up a new technology-based organization that is designed to help increase the ability of people to affect their own social mobility in Connecticut.

My intention here is not to talk about myself or my achievements, but to speak to the truth that I am so much more than my disability.

I can accomplish all these things because I currently have access to the care that I need through the MedConnect program – more specifically, the Community First Choice (CFC) program that allows me to hire Personal Care Assistants (PCA's) that aid me with the daily tasks of living independently.

The current income restriction for the MedConnect program is 75K a year... If I were to no longer be eligible for the program due to exceeding my income or asset restrictions, that would essentially be asking me to pay for the care that I need out of my own pocket. My PCA's are currently paid \$18.25/hr for 73hrs a week – that's approximately \$70K a year JUST to pay for my ability to get up in the morning and go to bed at night. If I am only making just over the \$75K limit, that is completely impossible! Why are we penalizing people with disabilities who are "too successful," with the threat of losing their very ability to function, their independence, their basic human needs?

As a young child I was involved in the planning and development of a playground in West Hartford – the first fully handicap-accessible playground in the state! I was asked to be part of the "dream and design" team, where children with various disabilities were asked about their dreams! – what did they dream of doing on a playground that they could never participate in before? It became one of the few places I could go where I was able to exist without boundaries or limitations – where I could dream big!

Every child deserves that experience. As kids, we are told to dream big, reach for the stars, and pursue our passions to find success as we grow up. Should those who are disabled and need assistance with the basic needs of daily living, be told that they have to compromise their abilities in order to claim their disability?

The income and asset limitations that are currently in place under the MedConnect program puts limitations on those dreams, and discriminates against people with disabilities and their ability to succeed in life and/or build something bigger than themselves.

My dream as a child was to play in an accessible playground treehouse, and become an artist when I grew up. I am lucky enough to have achieved both – but I'm not ready to stop dreaming! I never want to come to a point in life where I can't continue to grow and push myself simply because it would mean I would lose access to the care that I need to survive. I should not completely lose my independence because I exceeded people's expectations of what life can look like for someone like me. I – like anyone – have every right to the basic freedom of building a life that gives meaning and purpose, and that should be supported, not restricted.

Thank You,

**Carissa Decelles,**

Art Director, Designer & Consultant

[carissadecelles@gmail.com](mailto:carissadecelles@gmail.com)

860.712.5212